



**2nd Annual Sickle Cell Disease
Research and Educational Symposium
“Groundwork for Evidence-Based Practice Guidelines”
February 20-22, 2008**

**FORT LAUDERDALE GRANDE HOTEL & YACHT CLUB
FORT LAUDERDALE, FLORIDA**

THE PROGRAM-AT-A-GLANCE

7:00 a.m. – 5:00 p.m.	Registration
2:00 p.m. – 7:00 p.m.	Exhibits Open

Wednesday, February 20th

7:00 a.m. – 8:15 a.m. **Continental Breakfast**

8:15 a.m. – 10:00 a.m. PLENARY SESSION I

8:15 a.m.

Opening Remarks

Lanetta Bronte, MD, MPH, Director Sickle Cell Services

Memorial Regional Hospital

Atif Hussein, MD. Medical Director, Memorial Cancer Institute

SETTING THE STAGE FOR AN INTEGRATED HEALTH CARE MODEL

8:30 a.m.

Federal Perspective of the Sickle Cell Anemia Treatment Act

Michele Lloyd-Puryear, MD, PhD

Chief, Genetics Branch, Maternal & Child Health Bureau

9:00 a.m.

Sickle Cell Disease Partnership at National Heart Lung and Blood Institutes

Susan Shurin, MD

Deputy Director, National Heart Lung Blood Institute, National Institutes of Health

9:30 a.m.

National and International Sickle Cell Child Public Health Initiatives

Yvonne Maddox, PhD

*Deputy Director of the National Institute of Child Health and Human Development
National Institutes of Health*

10:00 a.m.

Break

10:15 a.m. – 11:45 a.m.

PLENARY SESSION II

10:15 a.m.

Role of National Coordinating Center in Health Care Delivery

Joseph Telfair, DrPH

Professor, Public Health Research and Practice

School of Health and Human Performance

- 10:40 a.m. **Genetic Services and Meaningful Outcome Measures**
Marie Mann, MD, MPH
Deputy Chief, Genetic Services Branch, Maternal and Child Health Bureau
- 11:05 a.m. **Sickle Cell Disease Association of America, Inc
Community Outreach and Bridging the Gap with
Community Based Organizations**
Willarda Edwards, MD, MBA
President and Chief Operating Officer, SCDA
- 11:30 a.m. **Sickle Cell Disease Summit – Challenges and Opportunities**
Kathryn Hassell, MD
Director, University of Colorado Sickle Cell Treatment and Research Center
- 12:00 p.m. -1:30 p.m. **LUNCH**
- 1:30 p.m. **INTRODUCTION OF JUNIOR INVESTIGATORS**
- 1:30 p.m. **Grant Writing Institute - Overview**
Betty Pace, MD, Chair, Grant Writing Institute
- 1:45 p.m. **Grant Writing Institute Presentations**
Junior Investigator 1
- 2:05 p.m. *Junior Investigator 2*
- 2:25 p.m. *Junior Investigator 3*
- 2:45 – 4:15 p.m. SIMULTANEOUS SESSIONS I**
- “WHAT DIVIDENDS HAVE BEEN GENERATED BY PAST RESEARCH”**
- 2:45 p.m. **NeuroPsych Comprehensive Sickle Cell Study**
Danny Armstrong, PhD
- 3:15 p.m. **Sickle Red Cell Endothelial Interactions**
Speaker Identified TBA
- 3:45 p.m. **Basic Research Progress**
Solomon Ofori-Acquah, PhD
Emory University School of Medicine
- “BUILDING COMMUNITY-BASED ORGANIZATION PARTNERSHIPS”**
- 2:45 p.m. **Fostering Community Partnerships**
Speaker Identified TBA
- 3:00 p.m. **Academic and Community Organization Partnership**
Marsha Treadwell, PhD, Director Patient Services Core
Mary Brown, President and CEO, Sickle Cell Disease Foundation of California
- 3:25 p.m. **Newborn Screening – NCEC Grantee**
Speaker Identified TBA
- 3:50 p.m. **Florida State Newborn Screening Model**
Iftikhar Hanif, MD
Director, Division of Pediatric Hematology/Oncology
Joe Dimaggio Children’s Hospital

4:15 p.m. **Break**

4:30 p.m. -6:00 p.m. SIMULTANEOUS SESSIONS II

“CURRENT THERAPY FOR CHILDREN WITH SICKLE CELL DISEASE”

4:30 p.m. **Hydroxyurea for Vaso-occlusive Complications in Children**
Russell Ware, MD

5:00 p.m. **Priapism, a Common Symptom in Males with Sickle Cell Disease**
Speaker Identified TBA e

5:30 p.m. **Warfarin Therapy in Sickle Cell Disease**
Kenneth Ataga, MD
University of North Carolina at Chapel Hill

4:30 p.m. -6:00 p.m. SIMULTANEOUS SESSIONS III

“Tissue Banks and Databases for Sickle Cell Disease”

4:30 p.m. **Sickle Cell Disease Patient Registry**
Speaker Identified TBA

5:00 p.m. **Electronic Medical Record – Coming of Age**
Speaker Identified TBA

5:30 p.m. **Comprehensive Sickle Cell Centers Tissue Bank**
Speaker Identified TBA

6:00 p.m. – 8:00 p.m. **Welcome Reception**
Albert Jones, South Broward Hospital District Board of Commissioners
Atif Hussein, MD – Medical Director, Memorial Cancer Institute
Sponsored By Sickle Cell Disease Association of America, Broward County

Thursday, February 21st

8:00 a.m. – 5:00 p.m.

Registration

8:00 a.m. – 7:00 p.m.

Exhibits Open

7:00 a.m. – 8:15 a.m.

Continental Breakfast

8:15 a.m. – 12:00 p.m.

PLENARY SESSION II

8:15 a.m.

Welcome and Introduction

*Stanley Marks, MD, FACS – Chief Medical Officer, Memorial Healthcare System
Kathy Hassell, MD -*

8:30 a.m.

How Far Have We Come? - Research Progress Update

*Ellen Werner, PhD
Acting Deputy Branch Chief Blood Diseases Branch
National Heart Lung and Blood Institutes, National Institutes of Health*

9:00 a.m.

Stem Cell Biology – Key to the Cure

*Allen Greenberg, MD
Memorial Cancer Institute*

9:30 a.m.

Introduction of Keynote Speaker

*Betty Pace, MD, Chief Medical Officer
Sickle Cell Disease Association of American*

9:35 a.m.

KEYNOTE ADDRESS: “STATE OF THE ART IN GENE THERAPY”

*Philippe Leboulch, MD
Associate Professor of Medicine, Harvard University*

**CURRENT STRUCTURE FOR GENERATING EVIDENCE-BASED
MEDICAL CARE PRACTICES; MOVING FROM CLINICAL TRIALS TO EVIDENCE-BASED
THERPY**

10:15 a.m.

Break

10:30 a.m.

The Comprehensive Sickle Cell Disease Center Structure

Kwafu Ohene-Frempong, MD

11:00 a.m.

The Sickle Cell Disease Clinical Research Network

Speaker Identified TBA

11:30 a.m.

Evidence-Based Therapy – The Nitric Oxide Clinical Trial

Speaker Identified TBA

12:00 p.m. – 1:45 p.m.

**Speaker Luncheon: BEST PRACTICES IN ACTION
MEDICAL CARE FOR SICKLE CELL DISEASE**

12:30 p.m.

Recognition and Appreciations

Lanetta Bronte, MD, MPH

12:50 p.m.

Introduction of Speaker

*Lennette Benjamin, MD
Professor, Clinical Director Comprehensive Sickle Cell Center
Albert Einstein College of Medicine*

1:00 p.m. **SPEAKER: DEVELOPING A BEST PRACTICE MODELS FOR SCD?**
Richard Lottenberg, MD
Professor of Medicine, Hematology/Oncology
University of Florida

2:00 p.m. -4:00 p.m. SIMULTANEOUS SESSIONS III

**Medical care for Individuals with Sickle Cell Disease;
Pain in Sickle Cell Disease**

2:00 p.m. **Acute Pain Management Approaches**
Samir Ballas, MD

2:30 p.m. **Quality Measurement and Improvement**
Wally Smith, MD

3:00 p.m. **Infectious Complication in Kenya**
John Waitumbi, DVM, PhD

3:30 p.m. **Best Practices Model for Common Complications**
Lennette Benjamin, MD

SIMULTANEOUS SESSIONS IV

Current Health Care Models for Sickle Cell Disease?

2:00 p.m. **Sickle Cell Disease Treatment Demonstration Project**
Speaker Identified TBA

2:15 p.m. **Federally Qualified Medical Clinics**
Maria del Pilar Aguinaga, PhD

2:40 p.m. **Role of Christian Health Care Ministries**
Speaker Identified TBA

3:05 p.m. **Health Care Delivery Model in Ohio**
Speaker Identified Thomas Webb, MD

3:30 p.m. **Best Practice Model for Pediatric Care**
Speaker Identified TBA

3:55 p.m. **Lessons from the Jamaican Cohort**
Graham Sergeant, MD

SIMULTANEOUS SESSIONS V

Challenges in Medical Care

2:00 p.m. **Role of Functional Genomics in Defining Clinical Phenotypes**
Martin Steinberg, MD

2:30 p.m. **Transfusion Therapy**
Allen Greenberg, MD, Memorial Cancer Institute

3:00 p.m.

Sickle Cell Lung Disease

Johnson Haynes, MD

3:30 p.m.

Best Practices Model for Adult Care

Cage Johnson, MD

4:00 p.m.

Hospital Unit for Adults with Sickle Cell Disease; Figuring out What Works?

Patricia Adams-Graves, MD

SIMULTANEOUS SESSIONS V

How can we establish a Transition to Adult Care Model?

2:00 p.m.

Kofie Anie, PhD, CPsychol

2:30 p.m.

Loretta Etienne, MSW

3:00 p.m.

Shawn Bediako, PhD

3:30 p.m.

Best Practice Model for Transition to Adult Care

Anne Schaefer, MD

Loretta Etienne, MSW

5:00 p.m. – 7:00 p.m.

Host Reception

J.E. Piriz, Senior Vice-President, East Operations

Memorial Healthcare System

Sponsored by Memorial Healthcare Volunteer Auxiliary

Friday, February 22nd

7:00 a.m. – 10:00 a.m.
8:00 a.m. – 12:00 p.m.

Registration
Exhibits Open

7:30 a.m. – 8:30 a.m.

Continental Breakfast

8:30 a.m. – 10:00 a.m.

PLENARY SESSION III

WHAT IS THE CURRENT REALTY?

8:30 a.m.

**Joint Commission Sickle Cell Disease Specific Certification
Implementing Change: Change Agent Model**

Lanetta Bronte, MD, MPH

9:00 a.m.

Medicaid Update and the Sickle Cell Treatment Act

*AHCA Representative
State of Florida*

9:30 a.m.

LifeBridge Life Insurance Program

Massachusetts Mutual Life Insurance Company
Robert Campbell

10:00 a.m.

Break

10:15 a.m. – 12:00 p.m.

**Best Practices Panel: Where do we go from here?
Implementation and Certification**

Panel to be selected – Focused Director's Clinical Panel

12 noon

Meeting Adjourned